

Sample Letter to Teacher, Principal, PE Teacher and Clinic Nurse

Dear _____,

My son, _____, is like other children his age in almost every way. He loves the same foods, games and stories. The only difference is that my son has a medical condition called hemophilia. He was born with this condition and will have it all his life.

About 17,000 Americans are affected by hemophilia, a blood clotting disorder. 36% of people with hemophilia are children under the age of 13. 99% of the people with hemophilia are male. It is not an infectious disease. A person with hemophilia has either an inactive or inadequate supply of one of the several factors needed for blood to clot normally. Like everyone else, it means when he accidentally bumps or cuts himself, he may bleed. He bleeds normally – no more, no less and no faster than you or I. He will not bleed to death in a short time. His bleeding just does not stop as quickly as yours.

Small cuts and scrapes are rarely a problem since they usually stop bleeding on their own. First-aid is the same for _____ as for other children (i.e. Band-Aid or ice and elevation, if appropriate). If _____ has a more serious injury, he may need an infusion of factor concentrate. Factor concentrate is given directly into his vein to help stop bleeding by a nurse who comes to our home, by me, or by _____ himself. We store this factor concentrate at home in our refrigerator. _____ may come to school on occasion with a heparin lock/shunt in place on the top of his hand. It is well wrapped in tape and gauze and he has learned to make do with it. We also try to have it placed on his non-dominant hand, but that's not always possible depending on his veins and where his bleed may be. This means we are treating a bleed for two or three days. Please do not be nervous about it. It has never fallen out, and if it were to, only pressure need be applied to stop the bleeding. Due to a chronic ankle bleed _____ was experiencing last year, he was on homebound schooling for the last couple of months of school. In the process, we started treating him prophylactically, which means he is treated three times a week to try to prevent some of his bleeding episodes. This has worked well for him and reduced these episodes.

Typical bleeds for _____ are in his joints and muscles. Some signs of a bleed that you might notice are limping, non-use of an arm or leg, swelling, or any unusual complaints. _____ may come right out and just tell you that something hurts. Many of his bleeds have no known obvious cause. They can be what are called spontaneous bleeds (from no specific injury). Many of them require only one or two treatments of factor, usually given once a day. He may have as many as two bleeds a month or go for two months without any. Please do not hesitate to have me called if his ankle swells or he starts to limp, favoring one foot when walking. He has been known to tiptoe when he has an ankle bleed.

Serious bleeds, but luckily rare, are bleeds in the head, throat, neck, abdomen, back and buttocks. He was once hospitalized for a neck bleed and has had several buttock bleeds when he was very little, but with no serious consequences. He has also had blood in his urine, which would indicate an internal bleed needing immediate attention. It scared him enough to tell an adult immediately. If _____ hits his head so you see it bounce, he loses consciousness, he cries excessively (more than you'd expect other kids to), or he later changes his demeanor, please call me or his dad.

If you are ever uncertain about whether or not to get in touch with me about _____, please do call. I do not mind being called and have a very understanding boss. I know how many situations with hemophilia are unclear. Sometimes we can be uncertain as to whether to treat him or not. If _____ needs an infusion of factor, I'll want to provide it for him as soon as possible.

No one, including teachers, other children or _____ will be blamed if he bleeds at school. I expect him to be treated as the other children are treated. He can participate in all classroom activities. The only rule we have with him is that he wear a bicycle helmet when riding a bicycle. Other children do not need to be cautioned to treat _____ with special care. He goes to school with many of his friends that he plays with in the neighborhood.

The school's public health nurse is well aware of _____'s condition, and I'm sure would be happy to speak with you as well. She and I have spoken in the past about _____ and his older sister who attends Chantilly High School and has mild hemophilia. She also had attended Virginia Run for 6 years. Karen McDonald, in the clinic, is very familiar with _____ and she and I have had much contact in the past. She usually knows exactly what to do before she even calls me. She has become very adept at accessing _____'s needs. As have his teachers in the past, I hope you will become comfortable with this before long. You may want to discuss your concerns with one of his prior teachers to put yourself at ease, or if you'd like I'd be happy to spend time with you, in person or by phone, to address any of your concerns.

As with any other child, please do not give _____ any medications. In particular, he is never to take aspirin due to its blood-thinning properties. He cannot use most over-the-counter medications due to their effect on the blood.

Again, please feel free to call me at any time.

Mother: _____ Home # _____
Work # _____
Cell # _____

Father _____ Cell # _____
Work# _____

Grandmother _____ Home # _____

Thank you,

cc: _____, Principal
_____, Clinic Nurse
_____, P.E. Teacher